

ORIGINAL ARTICLE

The fibromyalgia diagnosis – hardly helpful for the patients?

A qualitative focus group study

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Abstract

Objective. To explore experiences and consequences of the process of being diagnosed with fibromyalgia. **Design.** Qualitative focus-group study. **Setting.** Two local self-help groups. **Subjects.** Eleven women diagnosed with fibromyalgia. **Main outcome measures.** Descriptions of experiences and consequences of the process of being diagnosed with fibromyalgia. **Results.** Many participants had been suffering for years, and initial response of relief was common. For some, the diagnosis legitimized the symptoms as a disease, for others it felt better to suffer from fibromyalgia rather than more serious conditions. Nevertheless sadness and despair emerged when they discovered limitations in treatment options, respect, and understanding. Some patients keep the diagnosis to themselves since people seem to pay no attention to the name, or blatantly regard them as too cheerful or healthy looking. The initial blessing of the fibromyalgia diagnosis seems to be limited in the long run. The process of adapting to this diagnosis can be lonely and strenuous. **Conclusion.** A diagnosis may be significant when it provides the road to relief or legitimizes the patient's problems. The social and medical meaning of the fibromyalgia diagnosis appears to be more complex. Our findings propose that the diagnosis was hardly helpful for these patients.

Key Words: *Diagnosis, family practice, fibromyalgia, focus group, physician–patient relation*

Whether people define themselves as sick depends on whether the illness remains in the foreground or in the background of their lives [1]. Learning about the impact of illness, they gradually discover their losses of function, status, and self. Realizations about a failing body come when people try to live as before, while becoming socially identified and self-defined exclusively by their impaired bodies. Resilience reflects the notion that some people are more able than others to fend off the negative consequences of stressful experiences [2].

Significant turning points can emerge with meaning acquired through belonging, doing, and understanding the self or the world [3]. Hence, meaning in the context of chronic illness is as important for patients and clinicians as is the treatment of symptoms. Phenomenological analysis of the “worlds” of doctor and patient reveals a fundamental distinction between the lived experience of illness and its

Receiving a diagnosis can be one of many turning points in the lives of people with chronic disabilities.

- Naming is an important step in creating meaning. The fibromyalgia diagnosis may function as a preliminary recognition, but it does not hold the status of a medical condition, which provides relief from responsibility and stigmatization.
- When naming is difficult or regarded as negative, the doctor's challenge is to support the patient towards recovery by creating meaning beyond diagnosis.

conceptualization as a disease [4]. Receiving a diagnosis can be one of many turning points in the lives of people with chronic disabilities [2].

But clinical reality does not always present a diagnosis with the capacity to explain illness. Steihaug et al. [5] interviewed women with chronic pain attending training and group discussions. Many participants had experienced the pain as incomprehensible, while they described relief and understanding when given an explanation and acceptance of the pain. The pathophysiology, treatment, and prognosis of fibromyalgia are yet to be understood. From our experience in neurology and general practice, we knew the issue of diagnosis related to meaning might be especially significant for this group of patients.

We wanted to learn more about potential benefits and burdens of receiving the fibromyalgia diagnosis since it represents a medically unexplained disorder. We therefore undertook a study to explore experiences and consequences of the process of being diagnosed with fibromyalgia.

Design, material, and methods

We conducted a focus-group study with data from two interviews. A purposive sample recruited from two self-help groups represented group-wise variations on urban/rural residence and social class. Self-help groups were deliberately chosen, partly for opportunity reasons, but also to access experiences of individuals used to talking about their illness.

The sample consisted of 11 women between 42 and 67 years, reporting sickness duration of 8–40 years. Most of them had experienced symptoms for more than 30 years. Mean illness duration prior to diagnosis was 18 years (2–40 years), and after the diagnosis 15 years (5–20 years).

The interviews took place in premises familiar to the group. The second author (KM) was the moderator with the first author (MU) as secretary. The interviews dealt with experiences related to how the fibromyalgia diagnosis was arrived at, participants' emotional responses to this specific diagnosis, and the short-term and long-term consequences of the diagnosis in social life and healthcare.

Although some new issues appeared in the second interview, we concluded that the issues had been reported repeatedly and closed the data collection. Audiotapes of the conversations were transcribed verbatim. Data were analyzed by systematic text condensation [6,7], following four steps: (1) reading all the material to obtain an overall impression and bracketing previous preconceptions; (2) identifying units of meaning representing different aspects of participants' experience specifically related to receiving and presenting the fibromyalgia diagnosis, and coding for these units; (3) condensing and summarizing the contents of each of the coded

groups; and (4) generalizing descriptions and concepts concerning experiences with the fibromyalgia diagnosis. During analysis, both authors worked together, negotiating patterns and concepts interpreted from data, following an editing analysing style where theory supports the analysis rather than being a strict frame [8].

Results

Many participants had been suffering for years, and initial response of relief was common. For some, the diagnosis legitimized the symptoms as a disease, for others it felt better to suffer from fibromyalgia rather than more serious conditions. Nevertheless, sadness and despair emerged when they discovered limitations in treatment options, respect, and understanding. Some patients keep the diagnosis to themselves since people seem to pay no attention to the name, or blatantly regard them as too cheerful or healthy looking. The initial blessing of the fibromyalgia diagnosis seems to be limited in the long run. The process of adapting to this diagnosis can be lonely and strenuous. These findings are elaborated below.

Diagnostic uncertainty – medical reluctance

The fibromyalgia diagnosis came along different paths and at various points of their illness histories. After a while they saw their doctors, hoping for explanations and relief. Some participants were diagnosed by their GP, while others had been referred to specialists. Many of the women experienced how the doctor had difficulties explaining the symptoms. A woman in her forties said her doctor appeared unsure at first:

My doctor said all the way along that something was wrong, and that we had to figure out what it was. But I do not think he knew what it was at once, either. I believe he thought it would pass off. (P-4)

Quite often, the patient had arrived at the fibromyalgia diagnosis, recognizing symptom descriptions from the mass media. A shopkeeper in her early sixties described how since youth she had been told her aching back would recover. She heard about fibromyalgia on the radio, but the doctor did not acknowledge her proposal. Several participants described doctors who became hesitant or even blatantly dismissive, claiming that fibromyalgia was a fashion tag. A woman in her late forties who gave up her work as a saleswoman said:

When I came to the specialist I was told I had fibromyalgia, but she did not like to give me such a diagnosis since there is nothing to be done about it. It is just a word and according to this a newfangled thing. (P-7)

The relief of getting a name

All participants said that getting a name was a relief. Some of them had been convinced that something was seriously wrong. An aromatherapist in her mid-fifties felt that with a diagnosis she could finally regard it as a disease:

I felt happiness the day I finally got a name. For as long as I can remember something was always wrong with me, and it was a real problem during childhood and in my family. When I complained of aching they said: there is always something wrong with you. (P-3)

The diagnosis functioned to categorize the symptoms for these women. Eventually, they were able to tell their families about fibromyalgia. For one of the women, living in a rural area with challenging physical conditions, it gave initial relief to know that it was fibromyalgia rather than rheumatoid arthritis. A part-time working teacher was glad she could tell her husband about a less serious disease:

When I came home they were all relieved, and my husband said okay then we know that for sure. They were happy my illness was not something I would die from, because that is what they thought. (P-5)

However, negative attributions followed. Some of the women had never heard of fibromyalgia before, while others knew the diagnosis as stigmatizing. A middle-aged woman said she was disappointed, because she knew the word "fibromyalgia" would cling to her, even if she died of cancer or a heart attack. She never consulted her GP for other symptoms, fearing dismissal. Some participants referred to persons who suffered from debilitating symptoms named fibromyalgia, like this woman:

I felt paralyzed the first twenty-four hours. It was terrible, because I'd heard of this woman who was very sick with this disease. I thought my life would be turned upside down. It was a dreadful feeling. (P-10)

All participants said they had wanted their doctor to talk to them about the consequences. Several women expressed frustrations, because they wondered why they became sick. Many of them reported theories about illness causation.

Hardly helpful – when the diagnosis becomes a burden

After the first relief, most of the women experienced despair and sorrow when the content of the diagnosis was realized. Leaflets and internet pages pictured lifelong suffering and little treatment. This process was often a lonely one. A woman in her mid-sixties said that her doctor was very understanding and helpful trying to find a diagnosis but, according to him, the fibromyalgia diagnosis did not count for any welfare payment:

He wanted to help me, but did not write fibromyalgia since it did not gain any disability benefits back then. (P-2).

The women gave different accounts of their personal struggles. They felt disrespected by people who had heard of the diagnosis but still remarked that they did not look ill enough. One of the younger women said:

It is no use telling people you have fibromyalgia since they all seem to have something similar. People have come to me and said they have a touch of it, too. (P-4)

Another woman said that people seemed to expect improvement when she was diagnosed. Several described how difficult it is to explain about their suffering and disability. They realized that the "fibromyalgia" word was regarded as diffuse, and several of them found that it was a disadvantage to have a "women's disorder". They were told to learn to live with it, since the doctor somehow lost interest. Another woman described how she felt the doctor would give her all kinds of medicine if she just kept her mouth shut.

Some participants remarked that their doctor had classified fibromyalgia as just a word, associated with hysterical women, and even the specialist had called it a fashion disorder. Such degrading attitudes kept several of the participants from revealing the diagnosis, and some did not even accept the diagnosis themselves. They realized that they were considered to be difficult patients. One woman said it was a great shock when her doctor admitted that he disliked seeing her name and diagnosis on the list.

The woman still in search of another diagnosis asked for a referral to a neurologist, but the neurologist claimed that she had fibromyalgia without even examining her. A young woman who received a disability pension said the diagnosis did not gain any sympathy from those in her surroundings:

Nobody understood that you had fibromyalgia, and when you told them it felt like they did not notice or

they answered: is it just that. You felt the pain did not gain any respect, like they did not believe you. (P-8)

Discussion

These women describe a long road to a disputed diagnosis, and getting a name was initially relieving. However, negative attributions related to the diagnosis appeared. Many of the women experienced that the diagnosis did not in the long run count to legitimize their condition as a disease.

Talking about controversial issues

Women with medically unexplained disorders have reported scepticism and lack of comprehension during medical encounters. Werner [9] demonstrated the hard work to make symptoms socially visible, real, and physical when consulting a doctor, struggling for the maintenance of self-esteem and dignity. We therefore aimed at an interview context where such experiences should not be reproduced. Knowing about our profession, the participants may still have felt pressure to convince us about their credibility. The moderator made deliberate efforts to indicate that the research team did not question the legitimacy of their symptoms or diagnosis, in order to create a safe environment. Such attitudes may have inhibited comments from participants who were more reserved concerning the concept of fibromyalgia. However, we were also told stories about the limitations of this diagnosis.

Subjectivity and meaning

Wood [10] discusses the power of words and diagnosis in the context where doctors are at the juncture of medical knowledge and dealing with patients' experience of illness. Meaning develops in a sociocultural context where labels of illness are negotiated. Our participants told stories about events which had taken place some time ago. Recall bias was reduced by asking specifically for details about how they were diagnosed, and what happened then. Their stories are still constructed to embrace the meaning given to these events, which can be considered as a coping strategy to deal with the impact of a diagnosis for people suffering from conditions of medically unexplained origin, such as fibromyalgia. Subjective narratives can illustrate experiences of suffering as they address subjective meaning [11]. The stories illustrate some important perspectives of the process of being diagnosed with fibromyalgia experienced by these women, but it is

possible to read about even more negative feelings such as bitterness linked to losses in life, which is not the focus in this paper.

Transferability

Our sample represented variations regarding age, life situation, and illness experience. The women represented the decades when patients are mostly diagnosed with fibromyalgia. Similar stories would probably be recalled by numerous women suffering from chronic pain.

Members of a patient organization may differ from the average fibromyalgia patient in several respects. Our participants constitute a selected sample by experiencing the condition as a considerable part of their life, and coping by getting together. Their diagnostic experience and levels of functioning varied. For the purpose of our study, we therefore consider this to be asset of the sample. We do not know whether fibromyalgia patients with lower levels of illness-related social network speak differently about receiving a diagnosis.

However, people who join a self-help group search for a community, and such groups might reinforce a consensual understanding of the condition. This might be further strengthened by the focus-group approach. Our interviews still provided specific descriptions of very diverse events and attitudes, indicating that the group effect had functioned to foreground different experiences, rather than limiting the scope. Since both authors are doctors, participants may have felt a tension between withholding stories of negative experiences, as well as finally taking the chance of telling "the true story".

The self-help groups recruited women only. Men would broaden the aspects of meaning given to medically unexplained disorders, and should be included in further studies. There can be many reasons for seeking support in self-help groups, and women describing improvement of some kind are among our informants as well.

We chose fibromyalgia as an example of a medically unexplained disorder with some social acceptance. However, findings similar to ours may also be recognized in patients suffering from other unexplained disorders such as chronic fatigue syndrome (CFS) [12].

Diagnosis as recognition

In a Swedish study, women suffering from fibromyalgia and CFS experienced stigmatization primarily before receiving a diagnosis, due to the diffuse

symptomatology [13]. Our study reveals that stigmatization continues after the initial relief, since the name does not seem to invoke recognition from either doctors or lay people. Ogden et al. [14] found that medical labels were rated as beneficial for the patient in terms of validating the sick role and improving their confidence in the doctor. In contrast lay labels resulted in a greater sense of ownership of the problem, which could be associated with unwanted responsibility and blame. A hypothesis is thus that fibromyalgia is a diagnosis that does not hold the status of a medical condition which provides relief from responsibility.

Australian patients suffering from CFS highlighted the enabling aspects of the diagnosis [12]. A label allowed them to understand their experiences as coherent and meaningful, and to create a linguistic distinction between themselves and their illness, and they saw it as an essential precondition for coping. The same study reported doctors who felt reluctant about the CFS diagnosis, constrained by the scientific uncertainty regarding aetiology, and the diagnosis becoming a self-fulfilling prophecy. Our results support this view, but our informants also demonstrated the development of ambiguity concerning the diagnosis. The participants soon felt sadness and despair since the diagnosis did not gain appreciation as expected. Madden [15] illustrated how fibromyalgia is an empty diagnosis since it does not seem to be a meaningful label for the informants or for significant others. It therefore fails to produce a common language that can be used within social situations to explain the illness.

Patients tell of various coping strategies to avoid being exposed to enacted stigmas [13]. Turning points that ill people define as causing shock, sorrow, and shame require the greatest effort to transcend [1]. Charmaz [16] also describes how chronically ill people moving beyond loss and transcending stigmatizing labels define themselves as much more than their bodies and illness. Steihaug [5] reports how the battle for credibility becomes less intrusive in a person who feels recognized. Encountering such attitudes can open up new approaches and provide freedom of choice, independent of the name. Awareness in the doctor concerning his or her feelings is a foundation for the moral perception needed to prevent unintended degrading behaviour [17]. Our findings suggest that the fibromyalgia diagnosis may function as a preliminary recognition from the patient's point of view, but that this effect often reverses. The women describe how the long diagnostic process and the impact of the diagnosis is a long navigation towards a revised identity and self in which they miss the support from their doctor.

Implications

A diagnosis may be significant when it provides the road to relief, understanding, or legitimization of problems. The social and medical meaning of the fibromyalgia diagnosis appears to be more complex. For these patients, the diagnosis seemed hardly helpful after all. How, then, can physicians contribute to coping and support the construction of meaning for patients with medically unexplained disorders? How can the diagnosis function for this purpose?

The participants in our study convinced us that naming is an important step in the process of creating meaning for persons who find themselves increasingly disabled by a chronic condition. Yet, they have demonstrated the ambiguity attributed to a certain diagnosis. The challenge for the doctor is to tolerate the uncertainty of a diagnostic concept such as fibromyalgia, while supporting the individual patient in using the name of the disorder to create meaning in a life with chronic illness.

Acknowledgements

The authors would like to thank the participating women who shared their stories. This study received funding from the Norwegian Research Council and the Research Unit at the County Hospital of Buskerud Trust in Norway.

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